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TITLE: Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer

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## **Introduction**

Women at increased risk of Hereditary Breast and Ovarian Cancers (HBOC) and their families face dilemmas about testing, risk management and family dissemination of results on their own. They face problems regarding the accuracy of the information they have received, difficulties accessing new information and specialized services, and resistance and misinformation from inadequately informed health care professionals in the community. Thus, they are forced to develop their own informal means of individual and communal coping and to identify and access appropriate formal services without guidance.

Facing Our Risk of Cancer Empowered (FORCE) is a nonprofit organization and associated website ([www.facingourrisk.org](http://www.facingourrisk.org)) devoted exclusively to the community of women at risk for HBOC. FORCE serves important functions in the sharing of information, provision of support and active problem-solving, and in normalizing and validating the women's response to their predicament. This project involves evaluation of the activity and content of the FORCE website. All data is collected online and is completely anonymous. The project samples message board discussions for emergent issues and themes, recurring problems, and strategies for successful coping. Procedures include content analysis of archived threads and specific queries posed to a representative consumer board of women participating in FORCE activities. Additional analyses focus on the social structure of the FORCE community, how it is used by members of HBOC families, and how it reflects the unmet needs with respect to the medical system.

This project is intended to yield the basis for clinically useful tools to reach out to these women and better address their unmet needs. It will identify the specific tasks with which they need assistance and characterize forms of competent coping. Results will give impetus to new clinical, public policy, and research agendas for women and their families living with inherited risk of cancer.

## **Body**

This project was approved for data collection on May 17, 2004. Since that time we have downloaded more than 8,600 separate threads appearing on the FORCE message boards between August 1999 and September 2004, formatted and categorized the resulting text documents for compatibility with our analytic software program, QSR-N-VIVO, and entered and coded significant portions of the data to facilitate searches and detailed analyses.

Key members of the research team attended training sessions to become proficient in N-VIVO data management and analyses. In addition, we forged a collaboration with a qualitative sociologist who specializes in women's health and genetics—specifically issues related to HBOC. The combined efforts of our study investigators with expertise in qualitative and/or quantitative methodology facilitated detailed analyses of textual data with a degree of precision often lacking in purely qualitative research.

Initial quantitative analyses identified the themes of message board threads with the highest frequency and greatest activity. To date, we have combined quantitative and qualitative analyses to identify and examine one of the most frequently discussed topics on the message boards; decision-making regarding the use of hormone replacement therapy (HRT) following prophylactic oophorectomy (PO). Results of these analyses were presented at the *International*

*Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer* and a manuscript is currently in preparation and near completion. A poster summarizing the goals of the grant and its progress was presented at the June 2005 Department of Defense Era of Hope conference.

The second issue currently under investigation involves the decision to undergo prophylactic mastectomy (PM) and subsequent decisions concerning breast reconstruction. An abstract, *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board*, has been submitted for presentation at the 2006 Society of Behavioral Medicine annual meeting.

Although this project is still in the early stages of analyses, findings to date suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community. These women face potentially life altering decisions concerning risk management strategies and struggle to balance risk reduction and quality of life. The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. They experienced feelings of loss, as well as a changing sense of themselves as women during the adjustment to risk reducing prophylactic surgeries, and repeatedly expressed concern over the inadequacy of current research to address the issues most relevant to their health and quality of life. Specifically, studies that report the effects of HRT on menopausal women tend to focus on natural or surgical menopause in older women, but do not include younger high-risk women who have undergone surgical menopause for reduction of breast cancer risk. Nor do such studies explore the effects of alternate forms of HRT, including individualized bio-identical formulations. Controlled studies examining the impact of multiple forms of HRT on breast cancer risk in BRCA+ women following PO are warranted.

### **Key Research Accomplishments**

- Assembled investigator team
- Hired and trained research assistants
- Key personnel attended QSR-N-VIVO training
- Downloaded and converted entire FORCE archives HTML files to RTF format for use with QSR-N-VIVO, resulting in 5000 pages of searchable text documents
- Created a taxonomy of key issues warranting investigation based on frequency, volume, and duration of threads on the message boards
- Assembled FORCE consumer board for review and discussion of findings
- Completed analyses of first topic: Decisions surrounding the use of HRT following PO
- Presented early results at the *International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer*
- Preparation of first manuscript
- Analyses of second topic in progress: Decisions surrounding prophylactic mastectomy and breast reconstruction

## **Reportable Outcomes**

### **Completed Presentations:**

Coyne, J.C., (September, 2005). *So genetic testing is not traumatic, now what?* Invited Lecture: Grand rounds, Department of Medical Genetics, University of St. Andrews School of Medicine.

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (June, 2005). *Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board.* Paper presented at the 9th International Meeting on the Psychosocial Aspects of Genetic Testing for Hereditary Cancer, Philadelphia.

Palmer, S. C., Shapiro, P. J., Friedman, S., Coyne, J. C. (June 2005). *Using the Internet to Collaborate with Consumers in Redefining a Psychosocial Agenda for Families with Hereditary Breast Cancer.* Poster presented at the Department of Defense Era of Hope Conference, Philadelphia.

### **Work in Preparation or Under Review**

Kenen, R. H., Shapiro, P. J., Friedman, S., & Coyne, J. C. (2005) Peer-support in coping with medical uncertainty: Discussion of oophorectomy and hormone replacement therapy on a web-based message board. Manuscript in preparation.

Shapiro, P. J., Kenen, R. H., Hantsoo, L., & Coyne, J.C. (2005). *Decisions surrounding prophylactic mastectomy and breast reconstruction: Stories of grief, relief, and empowerment on a web-based message board.* Paper submitted for presentation at the 2005 Society of Behavioral Medicine Annual Meeting.

## **Conclusions**

This project is a unique collaboration between a multidisciplinary team of researchers and a non-profit organization that serves the needs of women and families affected by HBOC. Progress to date includes identification of key issues that affect both the immediate and long-term health and quality of life of women at genetic risk for breast and ovarian cancers. Detailed analyses integrating high-risk women's perspectives on these issues with the relevant medical and psychosocial literature are underway, with the first topic completed and the second topic near completion. In addition, we have identified a number of topics for future analyses, including exploration of 1) women's psychosocial and pragmatic support needs during significant events such as receipt of genetic test results, cancer diagnosis, and cancer recurrence, 2) unmet healthcare needs, 3) and satisfaction with physician care.

General findings suggest that women are profoundly affected by knowledge of their genetic status and actively seek medical information, experiential information, and emotional support from members of the FORCE community as a means of coping with potentially life altering decisions concerning risk management. The women who posted to the message boards were knowledgeable and proactive in their efforts to take control of their own health. In their struggle to balance risk reduction and quality of life, they repeatedly expressed frustration with the

inadequacy of current research to address these issues. In addition to their individual concerns, women expressed concern for their children and future generations. This project gives voice to their concerns—a collective voice in their own words with the potential to shape future clinical, public policy, and research agendas for women and their families who live with inherited risk of cancer.

## **References**

None

## **Appendices**

*None*